

Awesome day!!

What was?

Find out on page 3....

# red cell news

South Thames  
Sickle Cell &  
Thalassaemia  
Network

Issue 7 LATE SUMMER 2015

A newsletter for patients with sickle cell disease and thalassaemia

*Say hello, follow us on Twitter, give us feedback, send us your stories, photos, drawings or jokes, event news or other sickle cell and thalassaemia related stuff...*

[www.ststn.co.uk](http://www.ststn.co.uk) / [info@ststn.co.uk](mailto:info@ststn.co.uk) / +44 (0) 20 7848 5441 / @STSTNNetwork

## PATIENT SICKLE CELL AWARENESS DAY GUY'S & ST. THOMAS' NHS FOUNDATION TRUST



This year's Sickle Cell Awareness Day (above picture) was held by the Sickle Cell Team in the Sherman Lecture Theatre, Southwark Wing at Guy's Hospital on the 1<sup>st</sup> July as part of National Sickle Cell Awareness Week.

Forty people attended the day to listen to patients' own accounts of their experience of sickle cell disease, hear a range of presentations from medical, nursing, psychology and welfare staff and take part in a Q & A session with nursing staff.

Feedback from patients was very positive with most reporting that they found the day informative, well organised and interesting:

*"Very informative and encouraging to both patients and their families"*

*"Very worthwhile and informative, especially from a perspective of someone who hasn't had much previous knowledge of sickle cell"*

*"I learned from having other patients talk about their experiences. Thank you for organising this"*

Amongst the highlights for many who attended were: hearing from patients themselves, learning about current research in Sickle Cell Disease and learning about silent strokes.

Suggestions for next year's Sickle Cell Awareness Day included: allowing speakers more time to answer questions, increasing the number of patient speakers and providing notes / slides for attendees.



Dr. Tom Parsloe  
Clinical Psychologist,  
Health Psychology Service  
Guy's & St. Thomas' Hospital

A late summer hello from STSTN! The weather is always a hot (or not so hot!) topic and we think you'll agree, it's been a pretty wet and chilly summer! But, this hasn't stopped all the hardwork going on around the STSTN region.

In this issue, we bring you news from lots of events that have taken place over the last few months, most importantly the patient-focused events and support groups. **Keith James**, a patient at Guy's Hospital, shares his experiences of joining his local support group. A great read!

We also have our usual puzzles pages and some more jokes! If any of you are budding comedians, we would love to have a regular comedy corner, so send us your jokes for the next issue.

Finally, we have said goodbye to some very valued members of the haemoglobinopathy community who have moved on to pastures new! However, we also welcome new members of staff to hospitals in the region. See the back page for more details.

We hope you enjoy this issue. If you would like to get involved in the next one, you know what to do! Get in touch :)

Keep warm over winter and we'll be back next Spring!



Annabelle Kelly  
Manager  
South Thames Sickle  
Cell & Thalassaemia  
Network

## THE SICKLE CELL SUPPORT GROUP: MY EXPERIENCE

Guy's & St. Thomas' NHS Foundation Trust

By KEITH JAMES



I have known about the existence of the group for many years and like many of my peers with sickle cell disease I was resistant to attending.

*"Why do I need to go?" "I don't have any issues?"  
"What use is sitting around and talking going to do?"  
"What's the point?"*

All questions I used to say to myself, or respond to others with, when asked the question about participating. Even at times when I felt as though I could probably do with some extra help or support I was resistant. Maybe out of not wanting to appear weak or simply down to pride or stubbornness; I'm simply not sure.

However all that changed just under a year ago when Dr Heather Rawle saw me in clinic, and for the umpteenth time encouraged me to attend.

*"Why don't you go along and share some of your experiences of Sickle? You might help one of the younger members as well as gain deeper insight at the same time by doing so?"*

Somehow, that brief conversation between us tapped into something deep within me and the following Tuesday I attended for the very first time.

I wasn't quite sure what to expect at first but I was pleasantly surprised at how immediately comfortable I felt as I was welcomed in by the other attendees. It was only a small group of about six of us but I could feel that it was a very supportive environment. Anything that is

said within group time is confidential and whilst everyone is encouraged to share something, it wasn't compulsory. As a first timer I didn't think I was going to say much but on reflection I got stuck in and I found that I had plenty to offer and the hour and a half of group discussion flew by.

One aspect I did appreciate was that there is no official commitment to attend every week. Attendance is flexible and by no means compulsory which helps to fit in with the complexities of life with sickle cell disease. Fast forward to now and I have been a regular attendee of the support group for almost a year. The topics that we have shared and discussed have been wide and varied. For example, managing sickle whilst at college, university or work; sleep patterns; stigma; pain management; parenting; wider support networks and blood transfusions.

These are just some examples of subject matter that we have covered recently and what I like best is that we don't just talk about a subject and then move on. Rather, we are each encouraged to share our experience or knowledge on said topic (if any). By doing so we often pick up and learn new skills or coping methods to use from each other. As with anything some work better than others or will be more useful to one person than another. Sharing views and strategies within the support group has not only helped us deal with our chronic illness in differing ways it has also helped to form new bonds and friendships along the way too.

I now find myself singing the praises of the Sickle Cell Support Group. When I see my peers, whether I am in clinic or in the day unit, I encourage them to come along and give it a try. I'm pleased to say some have done exactly that and are reaping the benefits. So come on in and join us, there's always room for one more.

To join the Guy's & St. Thomas' Sickle Cell Support Group, please contact:  
Mina Abedian  
02071882718 / [Mina.Abedian@gstt.nhs.uk](mailto:Mina.Abedian@gstt.nhs.uk)

## OTHER PATIENT SUPPORT GROUPS:

### KING'S COLLEGE HOSPITAL NHS FOUNDATION TRUST

*(For King's College Hospital patients only)*

This group aims to hold meetings on the 2nd Friday of alternate months: the next meeting is scheduled for 9th October 2015 (please confirm with contact below)

It is from 5:00pm - 7:00pm and is for adults and younger patients transitioning to adult service

KCH patients are sent invites in the post.

Contact: Chengetai Muzah  
Sickle Cell and Thalassaemia Clinical Nurse Specialist,  
King's College Hospital  
Tel: 0203 299 1400

**DO YOU HAVE A PATIENT SUPPORT  
GROUP IN YOUR AREA?**

Email [info@ststn.co.uk](mailto:info@ststn.co.uk) with details

## THE CHILDREN'S WORKSHOP

King's College Hospital NHS Foundation Trust

By Dr Jo Blundell

Clinical Psychologist, Paediatric Sickle Cell & Thalassaemia Team

In June 2015, the Paediatric Sickle Cell and Thalassaemia Team at King's College Hospital held their first Children's Workshop event.

### What is The Children's Workshop?

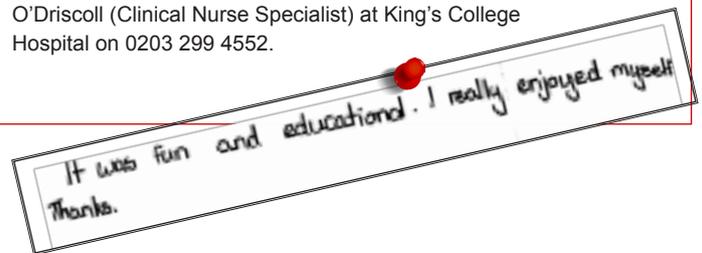
The Children's Workshop was developed for children between the ages of 6-10 years old with sickle cell disease. It aims to bring children with sickle cell together to learn more about their condition in a fun and interesting way.

### What did we do at the workshop?

There were loads of different activities and games that we did at the workshop but some of our time included playing, laughing, writing, talking, thinking, imagining, listening to stories, caring and meeting 'Morgan the Organ Robot'!

### Who came to the workshop?

19 children aged between 6 and 10 years old came to the workshop. It was fantastic to see so many faces! The workshop was hosted by members of the multi-disciplinary paediatric team including Sandra O'Driscoll (Clinical Nurse Specialist), Kemi Johnson (Community Sickle Cell Nurse) and Jo Blundell (Psychologist).



### More information?

The Paediatric Sickle Cell & Thalassaemia Team at King's College Hospital run a range of workshops for children and young people with sickle cell and thalassaemia including The Children's Workshop, The Young People's Workshop and a Transition Open Day event. If you would like more information about the next Children's Workshop or any other workshop that we run then please contact Sandra O'Driscoll (Clinical Nurse Specialist) at King's College Hospital on 0203 299 4552.

## ADOLESCENT SUPPORT GROUP MEETING 26th August 2015

Guy's & St. Thomas' NHS Foundation Trust

By **Luhanga Musumadi MPH, BSc, RGN**

Advanced Nurse Practitioner, Adolescent Transition for Haemoglobinopathies, Guy's Hospital

Despite the threat of tube strike action and the usual August heavy rain, a smaller than usual but very enthusiastic group of our transitioning patients here at Guy's Hospital attended a special meeting on *Making the Most of Life After College*.

The aim of the meeting was to provide advice and support

to our younger patients who are now making those important decisions either before heading to college or university or what to do next after graduation.

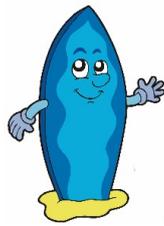
The day went really well and discussions hinged predominantly around preparing for higher education and addressing the anxieties of living independently away from home. We had a lecturer from King's College London talking about student support issues, particularly for young people with chronic conditions.

Great discussions!

For more information contact: [Luhanga.Musumadi@gstt.nhs.uk](mailto:Luhanga.Musumadi@gstt.nhs.uk) or mobile: 07770678851.

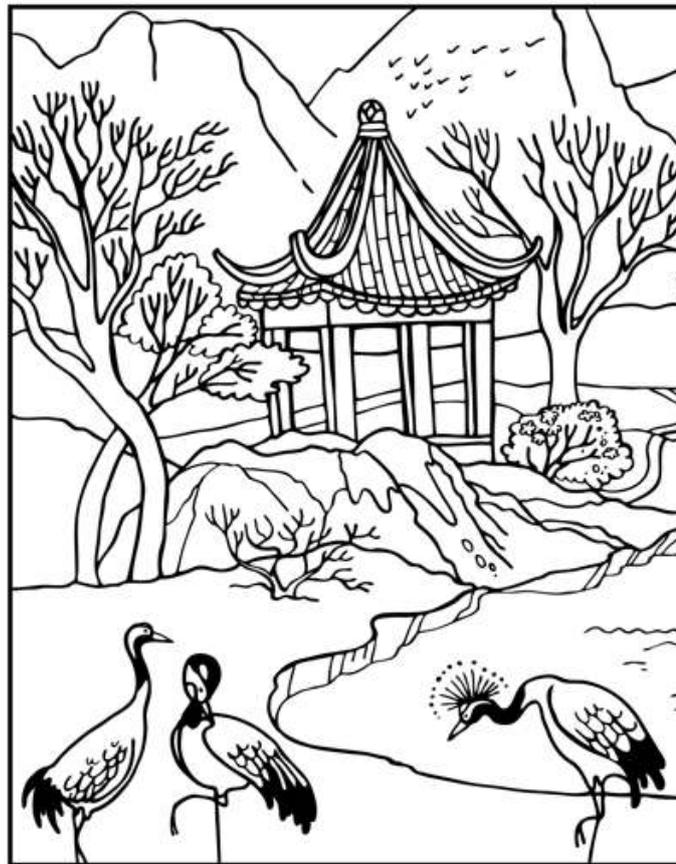


# Summer Holiday Word Search

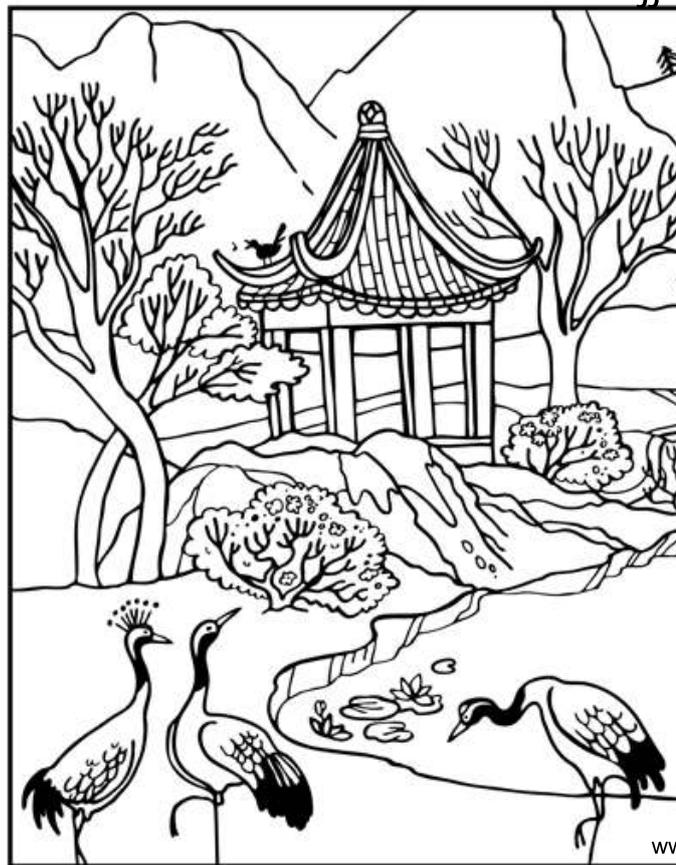


t	h	x	d	l	v	n	d	p	u	m	t	b	x	d
s	h	o	p	m	c	v	k	t	m	s	m	f	p	q
u	t	y	t	m	w	r	d	i	p	x	d	v	t	q
i	x	e	l	e	g	j	d	c	w	y	i	m	b	s
t	k	c	n	z	l	c	n	e	w	j	j	k	u	m
c	x	w	w	t	d	c	u	c	g	n	w	m	w	i
a	t	j	n	h	r	a	o	r	b	a	m	r	d	o
s	b	f	d	r	a	g	r	e	l	e	y	n	n	x
e	m	y	p	p	c	k	g	a	r	h	z	m	u	r
f	z	a	a	s	t	w	r	m	c	r	g	y	i	v
y	e	w	c	w	s	h	i	y	e	n	r	u	o	j
l	f	w	k	i	o	i	a	k	i	p	y	l	h	m
g	f	v	c	m	p	b	f	x	e	i	b	f	a	h
u	f	f	x	x	g	x	z	i	k	y	y	p	u	x
n	u	m	k	y	r	s	y	l	i	m	a	f	l	n

- |            |        |          |          |          |
|------------|--------|----------|----------|----------|
| fairground | family | fun      | hotel    | icecream |
| journey    | pack   | postcard | suitcase | summer   |
| swim       | tent   |          |          |          |



Find the difference



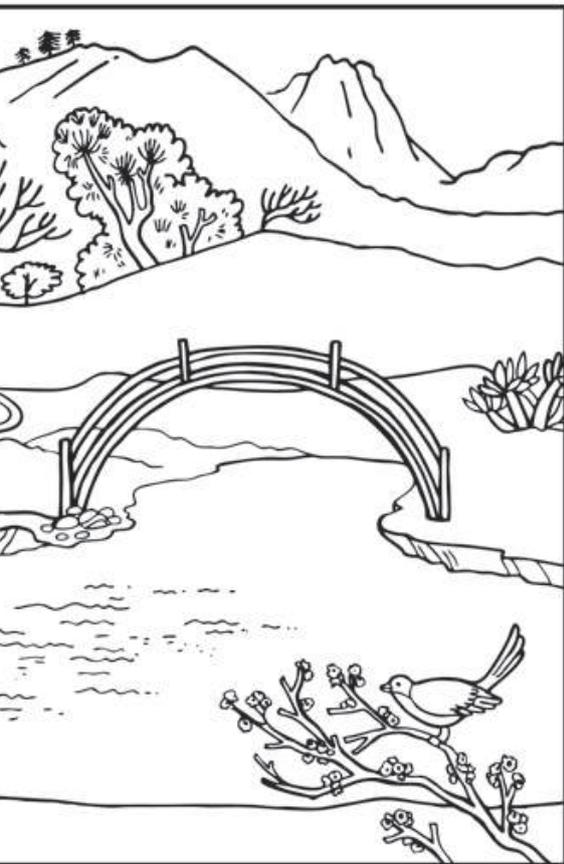
## COMEDY CORNER

I've lost my dog. What shall I do?  
Why not put an advert in the local paper?  
Don't be silly, my dog can't read.

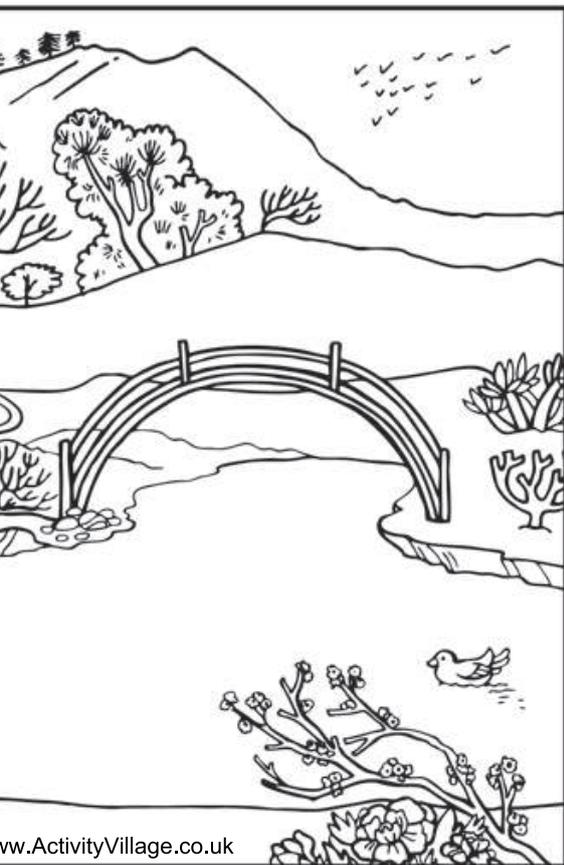
How can you find a really cool website?  
Put your computer in the fridge.

Doctor, doctor, do I need glasses?  
You certainly do, this is a greengrocers's.

Thanks to Linda Falzarano, Youth Worker at King's  
College Hospital NHS Foundation Trust



ferences

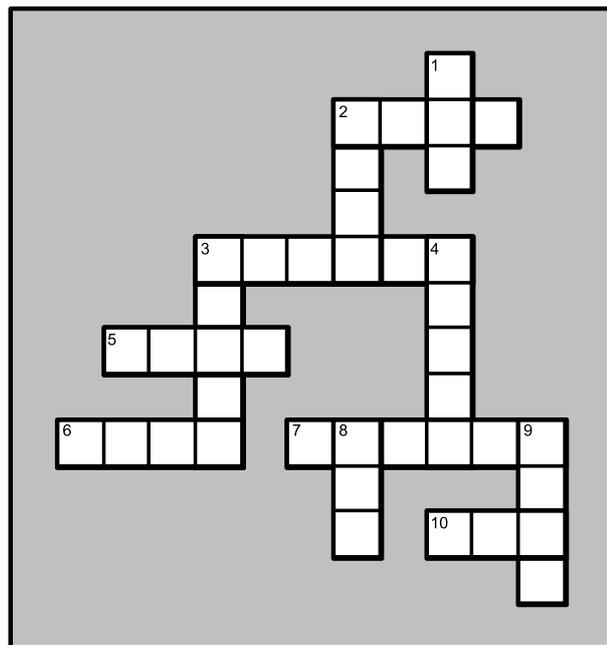


[www.ActivityVillage.co.uk](http://www.ActivityVillage.co.uk)

DO YOU HAVE A STORY TO TELL?  
ARE YOU A GRAPHIC DESIGNER,  
PHOTOGRAPHER, OR ILLUSTRATOR? OR A  
BUDDING COMEDIAN WHO WOULD LIKE  
TO SHARE SOME JOKES?

red cell *news* WOULD LOVE TO HEAR FROM YOU! PLEASE  
GET IN TOUCH IF YOU WOULD LIKE TO BE INVOLVED IN  
YOUR PATIENT NEWSLETTER: [INFO@STSTSN.CO.UK](mailto:INFO@STSTSN.CO.UK)

## Seaside Crossword



### Across

2. It may have a sail or oars
3. Perhaps you could collect water in this?
5. Watch him scurry down his hole
6. They swim in the sea and have scales and fins
7. She sells sea \_ \_ \_ \_ \_ on the sea-shore
10. I hope this is out for your holiday

### Down

1. Carry your beach things in this
2. A good read!
3. The strip of sand along the sea shore
4. Dry yourself with this
8. Wear one of these to keep the sun off your head!
9. It feels funny under your toes

# OTHER EVENTS

## ANOTHER FANTASTIC TURNOUT FOR THE 9TH SICKLE CELL IN FOCUS CONFERENCE LONDON, 15-16 JUNE 2015

Once again, more than 100 guests from around the world joined Programme Directors, Professor Swee Lay Thein and Dr John Tisdale, for the 9th Sickle Cell Focus conference.

This year, the programme included the trials and tribulations of developing phamacotherapy, the ongoing debate about the use of hydroxyurea, new developments in genomics and genome editing and a closer look at haemolysis following recent publications and controversies.

As ever, we were grateful to all our speakers and delegates, and our financial supporters who make this event possible.

See you in Washington for the 10th conference, 2-3 June 2016!



Professor Kwaku Ohene-Frempong poses a question to the panel



(L-R) Drs Russell Ware and Miguel Abboud debate the use of hydroxyurea.

The audience at The Light @ Euston



### SICKLE CELL SOCIETY'S ANNUAL SERVICE OF REMEMBRANCE AND THANKSGIVING

The Sickle Cell Society and The South East London Sickle Cell and Thalassaemia Centre Nurses with the Mayor of Lambeth at the Sickle Cell Society's annual service of Remembrance and Thanksgiving at St Mark's Church, Kennington on 21 June 2015.



From left: Emma Gedeon, Councillor Donatus Anyanwu, Yvonne Owusu –Sekeyere, Patience Ologe, Iyamide Thomas and Daniel Nyakutsey

### WORLD SICKLE CELL DAY COMMEMORATION ABUJA, NIGERIA

A group of sickle cell disease specialists from the UK was able to participate in the 2015 World Sickle Cell Day commemoration in Abuja, Nigeria, thanks to sponsorship by the British High Commission in Nigeria.

solutions for diagnostics and treatment. Nigeria is the country with the largest number of sickle cell disease patients worldwide.

*Dr Stephan Menzel  
Senior Lecturer  
Department of Molecular Haematology  
King's College London*

A Research Workshop took place involving British and Nigerian colleagues with the aim to start working together towards lightening the burden of the condition and finding new



(Left) The British delegation (from left to right): Dr Rosemary Ekong, University College London, Prof Imelda Bates, Liverpool School of Tropical Medicine, Dr Stephan Menzel, King's College London, Dr Baba Inusa, Evelina Children's Hospital, London, Dr Yvonne Daniel, Viapath, Guy's and St Thomas' Hospital London and Dr Fred Piel, University of Oxford.

(Below) Some of the attendees



### UPCOMING EVENT

#### THE 9TH ANNUAL SICKLE CELL AND THALASSAEMIA ADVANCED CONFERENCE

7-9 October 2015, The Hilton Tower Bridge, London

Programme Director: Dr Baba Inusa, Evelina Children's Hospital

Book online: <http://bit.ly/1Jf4ZRz>

## THE SICKLE CELL SOCIETY'S 36TH ANNUAL GENERAL MEETING &amp; EDUCATION DAY



By ZOE WILLIAMS,  
COMMUNICATIONS AND SOCIAL  
MEDIA OFFICER, SICKLE CELL  
SOCIETY

The Sickle Cell Society held its 36th Annual General Meeting and Education Day on 18th July in the Grand Connaught Rooms in Central London. More than 130 people attended from all over the UK, from Kent to Scotland, with hundreds more following the proceedings online. The audience and speakers were a mixture of those living with sickle cell disorders, carers, healthcare professionals and business people. Jennifer Mann, Mayor of Haringey, was also in attendance, as the borough of Haringey has a high prevalence of sickle cell disorders.

The morning was taken up with AGM business, and a look back at a successful year for the Society. The Sickle Cell Society launched two new projects: a support service for Brent residents who had been recently discharged from hospital, and a project to develop a peer-to-peer support network in Hackney. The Society has also undertaken parliamentary work to raise awareness of sickle cell in hospitals, worked with the NHS Screening Programme to help identify carriers of the gene, and taken children with sickle cell on a specially-tailored holiday.

As the event broke for lunch, a lively discussion

broke out about patients' experience of a lack of awareness among medical professionals. Fittingly, the afternoon session opened with a presentation from Patrick Ojeer about a new tool for measuring patient experiences. This short questionnaire was developed based on feedback from focus groups of people living with sickle cell disorders and will be able to quantify problems patients have encountered so that improvements can be made where necessary. The Patient-Reported Experience Measure was developed by North West London CLAHRC and the Picker Institute.

The second talk of the Education Day portion was on In Utero Stem Cell Transplantation, presented by Dr Stavros Loukogeorgakis (pictured below) of University College London.



Stem cell transplants (also known as bone marrow transplants) are acknowledged to be a cure for sickle cell disorders, but are not without risks: the success rate is highest in those patients who have a healthy and fully matched sibling to donate stem cell, but does

carry a small risk of death as a result of the procedure. However, if the stem cell transplant is undertaken on a baby before it is born, the stem cells do not have to be so strictly matched as the immune system is not so fully developed. While this development is very much in its infancy, and has yet to be trialled on humans, it looks like a promising way of curing sickle cell before a child is even born!



Following a Q&A session facilitated by Professor Elizabeth Anionwu, a patron of the Sickle Cell Society, it was time to award prizes. Gary A. Swaby (pictured above) was awarded the prestigious Floella Benjamin Achievement Award for his hard work in blogging his life with sickle cell disease, and his contribution to raising awareness.

To stay in touch with the Sickle Cell Society, please visit our website:

[www.sicklecellsociety.org](http://www.sicklecellsociety.org).

See you at the 37th AGM!

## UPCOMING EVENT

## The Sickle Cell Story – History, Legacy, Achievements

Friday, 2 October 2015, 6.30pm – 10.30pm @ The Crypt, St Peter's Church, Liverpool Grove, London SE17 2HH

How much do you know about sickle cell? Do you know it is the most commonly inherited blood condition in the world? Do you know that over 30 years before its Western 'discovery' in 1910 a West African medical doctor wrote a publication describing a condition with a 'constant abnormality of blood which had a peculiar tendency to be prevalent among natives of the Tropics, who then suffered more in the rainy season'? That condition described as far back as 1874 is what is thought to have become known as sickle cell anaemia!

The UK Black Community has struggled to raise awareness and achieve better care and equity for families affected by sickle cell disease and as part of Southwark Council's Black History Month 2015 official programme the Sickle Cell Society will put on an innovative event which through film, presentations, discussion, personal stories and comedy

will celebrate and chart the unique history, legacy and achievements in sickle cell.

There will be a special screening of *'The Family Legacy'*, a British/Nigerian drama about the emotional journey one family makes when their baby is born with sickle cell disease. There will also be an inspirational figure in the sickle cell world who himself had sickle cell disease but succeeded in becoming a world renowned Consultant Haematologist looking after patients with sickle cell. People living with sickle cell will talk about achievements in their lives and show that despite living with a debilitating condition, they too are 'Fit to Achieve', Southwark's Black History Month theme for 2015. There will be a panel discussion with sickle cell experts and to round off the evening, entertainment will be provided by a comedian living with sickle cell disease!

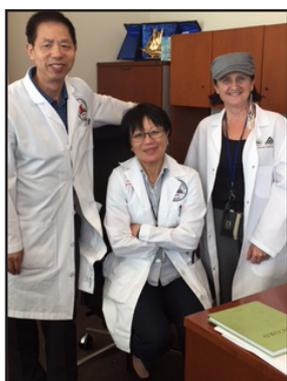
To reserve your FREE ticket, please visit:  
[bit.ly/sicklestory](http://bit.ly/sicklestory)

For further information contact Ms Iyamide Thomas, Sickle Cell Society:

Email: [iyamide.thomas@sicklecellsociety.org](mailto:iyamide.thomas@sicklecellsociety.org)

# STAFF UPDATES: GOODBYES AND HELLOS!

## PROFESSOR SWEE LAY THEIN TAKES UP ROLE AS DIRECTOR OF THE SICKLE CELL BRANCH AT THE NATIONAL INSTITUTES OF HEALTH, USA



Above: Professor Thein with colleagues at NHLBI

Many of you will know by now that after 15 years of working as a Consultant at King's College Hospital NHS Foundation Trust (KCH) and leading the Department of Molecular

Haematology at King's College London (KCL), I have taken up a very exciting role as the Director of the Sickle Cell Branch at the prestigious National Heart, Lung and Blood Institute (NHLBI), The National Institutes of Health (NIH) in Bethesda (near Washington DC), USA.

Come September when this issue of Red Cell News is out, I would have been here 6 months. Settling into my new role here has not been as difficult as I had expected. I have many ready-made colleagues and friends.

My role here is very much doing what I have been doing in King's – patient care, research and education. Ongoing

research program includes bone marrow transplant (Drs. John Tisdale, Matt Hsieh, and Courtney Fitzhugh), gene therapy (Dr. John Tisdale), understanding sickle pain (Dr Jim Taylor), vascular pathobiology (Dr. Hans Ackerman), clinical trials on anti-sickling therapy (pharmacotherapy including fetal Hemoglobin induction, and genomic approaches). I will also be starting a couple of my own protocols soon.

My appointment at NHLBI now increases the opportunities with King's and other Trusts within the STSTN region for



Left: King's College Hospital patient, Siju, at his recent six month follow up, with Professor Thein and his father at NHLBI

collaboration in terms of clinical research and educational events. Just recently in June, I was back in London hosting the 9th Sickle Cell in Focus conference, which will now be alternated between London and Bethesda. You can see some pictures from the event on page 6. We are now working on the 10th SCiF in

2016 and I do hope that I will see at least some of you here next year.

I am very sad to leave behind the valued relationships I have built with my patients and colleagues over the years. I had a hugely rewarding time at KCH and KCL. But I am relishing my new role and being part of a new team engaging in exciting and important research into sickle cell disease.

With warm wishes from the USA accompanied by massive sunshine!!!

Swee Lay Thein.



Above: Siju with King's College Hospital staff at the NHLBI in September 2014, where he went for some pioneering bone marrow transplant treatment

## HELLOS:

### EVELINA CHILDREN'S HOSPITAL

*Dr Maria Pelidis has joined as Consultant Paediatric Haematologist*

*Mrs Abidemi Olateju has joined the team as Clinical Nurse Specialist.*

### KING'S COLLEGE HOSPITAL

*Subarna Chakravorty has joined the team as Consultant Paediatric Haematologist.*

*And we also say hello to Anne Mwirigi, who has joined the the adult sickle team as a Locum Consultant Haematologist.*

## GOODBYES:

### EVELINA CHILDREN'S HOSPITAL

*Dr Jiafeng Feng data manager and research assistance has left to join Imaging and Sciences, Raynes's Unit, St Thomas site, King's College London.*

### KING'S COLLEGE HOSPITAL

*After many years as a Clinical Nurse Specialist Marlene Allman has sadly left the team at King's College Hospital, joining the Department of Molecular Haematology at King's College London as a Clinical Trials Nurse.*

red cell news is produced by the South Thames Sickle Cell & Thalasassaemia Network (STSTN), a haemoglobinopathy network led by Consultants from King's College, Guy's and St. Thomas' and the Evelina Children's Hospitals.

Our goal is to improve the patient experience by offering better treatment outcomes for people with sickle cell disease and thalassaemia.

To find out more, please visit [www.ststn.co.uk](http://www.ststn.co.uk)

Disclaimer:  
STSTN is a large network that includes many different people.

The opinions of contributors in this newsletter are those of the individual authors, and not necessarily shared by everyone involved in STSTN.

STSTN does its best to ensure the accuracy of content, but accepts no responsibility for any errors in individual articles.